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Value of Personal Health Records for Patients, Citizens & Science

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Last week saw strong reactions to a proposed rollback of the requirement for US health organizations to demonstrate *patient engagement* with electronic health records as a condition for HITECH incentive payments. Much of this stemmed from an impassioned speech at the HIMSS conference by the former US National Coordinator for Health IT, Farzad Mostashari, who'd spent much of his time in office trying to facilitate this. (1)

The original expectation of at least 5% of patients using a personal health record or portal to access their data, has been watered down to only *one* patient, merely to indicate that the technology is in place. The patient empowerment and e-patient communities have interpreted this as a major slap in the face, with passions running high online and a flurry of activity on social media. (2)

Although lack of access to such technologies is the number one barrier to patient record access on both sides of the Atlantic, there are now some well-embedded examples, particularly in major US health organisations but also in UK primary care and elsewhere, and modest evidence is beginning to accumulate of benefits to some patients and providers. (3) Unfortunately what has also become apparent is that relatively few patients actually make use of these tools even when they are available to them. For those of us dedicated to improving patient health through technology, responding to this uncomfortable truth is a challenge but one that we must deal with. Patients who are not ill, managing a long-term condition, undergoing a procedure or filling in insurance forms have little incentive to look at their medical record. That describes most of us, most of the time. This can disguise the benefits for specific groups when evaluating record access across general patient populations and further research is needed to understand the types of users most likely to benefit and the components of complex

systems that are most likely to help. (4) The rise of personal data platforms like Apple's HealthKit may shed new light on some of these nuances, but here we're mainly talking about the records held by healthcare providers.

Despite these inconveniences, it is indisputable that as a society, and as health professionals, we need to do much more to empower people to engage in preventive and wellness behaviours, and motivating patients to use their health record for information, self-tracking, or as an aid to shared decision-making is an important part of this. This is easier said than done, considering that conditions like Type 2 diabetes often arise, at least in part, through a lack of health motivation in the first place – something that can be overlooked in eloquent narratives by enthusiasts like e-Patient Dave. Key challenges lie in raising awareness, making systems usable and genuinely useful for patients, overcoming professional and patient resistance to the idea that personal data will be somehow 'let loose', with risks to privacy, and convincing purchasers that it's worth the money to invest in implementing and maintaining these services.

I strongly disagree with the argument that because record access technologies aren't going to be actively used by the majority they should be relegated down the priority list for health systems. What's critical here is ensuring that, as citizens, we have the means by which to exercise our *rights* to see and, if appropriate, interact with our health information should we wish or need to. Whether or not this right is acted upon, it's an equally valid reason for making such systems more widely available. With citizen digital empowerment and data rights high on the European policy agenda (not just for health) it's likely that this will drive political decision making on this side of the pond just as much as the health improvement agenda, and many governments are currently wrestling with how to deliver these 'ICT-enabled benefits for society'. (5)

There are other, less obvious but equally important, reasons for investing in these patient-centric technologies, which have implications for science and policy. Highly publicised data breaches, the Snowden revelations and concerns about misuse of personal information in many countries – typified by the furore over care.data in the United Kingdom (6) – have triggered the suspicion which is driving many people to actively opt out of sharing their data for *bone fide* research purposes. This presents risks for understanding health trends and inequalities, evaluating the impacts of new interventions and progressing innovations in personalized medicine. Policymakers need to be aware that the Return on Investment in personal health record systems will come not just from the theorized clinical and financial benefits of record access but, significantly, through the *trust* that comes with being open with patients about the data that is held about them.

In light of these various risks, the apparent de-prioritisation of patient engagement signaled by the changed US requirements is of concern, although it may simply reflect the inevitable reality of trying to get complex systems in place within over-optimistic timescales. Hopefully a statement of long-term intent will help to dispel this impression, but other countries should take note of the reaction.

Key words: Electronic Health Record. Personal Health Record. Personalised Medicine. Data rights. Privacy. Patient empowerment. Research. Public attitudes.

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Dr. E Beratarbide (My views only)

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IG Advisor at The Scottish Government (eHealth) - IG Lead for NHS - Health Informatics Tutor...

Interesting ideas, Claudia, and no less shocking results... 1 patient only ? not even the expected 5%? shocking !

I suppose we have to accept the reality and learn from it.

I agree with all the reason presented here, specially regarding lack of trust in appropriate data protection, as IG Lead I only can sympathise with this concerns, and will get worse before gets better b

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Thanks Nuno. You’re right about the need to see the whole person, to think about how people fit these sorts of technologies into their lives, and to co-design systems with users and providers of services, which are good principles for all of digital health. The PHR space is complicated by the need to separate but also to somehow bridge provider-owned and patient-owned data... [See more](#)

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